HRBA

Health Record Banking Alliance

Principles

Consumer Ownership and Control of Health Records

1. Health record banks protect the individual consumer's right to health information privacy and confidentiality by acting as trusted legal custodians of consumers' health records.
2. Health record banks are repositories for trustworthy copies of health information selected or submitted by the consumer from various sources.
3. Health information in a health record bank is owned by the consumer and is not an asset of the health record bank.
4. Consumers may authorize someone else to manage their health record bank account.
5. Health record banks provide consumers and others they authorize with immediate electronic access to their health information.
6. Consumers control all disclosures of their health information by a health record bank unless otherwise required by law.
7. With consumer consent based on advance disclosure appropriate to the circumstances, health record banks enable secondary use of health information, such as for public health and research purposes.

Operation of Health Record Banks

8. Health record banks are governed in an open, accountable, and transparent manner.
9. All access and updates to information in health record banks are recorded as they occur in an appropriately detailed audit trail database, and each health record bank shall maintain those unaltered audit records at least during the time that a consumer's health record is kept at the bank and make those audit records immediately accessible to consumers.
10. Health record banks have established processes for correcting errors by updating, amending, and sequestering data, including mechanisms for notification of parties who have received such data.
11. Health record banks promptly disclose breaches of privacy, confidentiality, or security to consumers.

Operation of the Health Record Banking Alliance

12. The Health Record Banking Alliance seeks to maintain neutrality among vendors that agree to adhere to the above principles.

Definitions used in the statement of principles

Health information privacy refers to an individual's right to control the acquisition, use, or disclosure of his or her identifiable health data. Confidentiality refers to the obligations of those who receive information to respect the privacy interests of those to whom the data relate. Security refers to the physical, technological, or administrative safeguards or tools used to protect identifiable health data from unwarranted access or disclosure. (Derived from a letter from the National Committee on Vital and Health Statistics to the Secretary of HHS sent 6/22/06. Available at http://www.ncvhs.hhs.gov/060622lt.htm , accessed 5/9/07)

What is a Health Record Bank?

A health record bank or trust is an independent organization that provides a secure electronic repository for storing and maintaining an individual's lifetime health and medical records from multiple sources and assuring that the individual always has complete control over who accesses their information.

About the Health Record Banking Alliance

The Health Record Banking Alliance is a non-profit 501(c)6 organization formed to assist stakeholders in the promotion of community repositories of health records to improve the safety and efficiency of patient care.

Vision

Enable improvements in health care, public health, and medical research through the availability of comprehensive and secure lifetime electronic health records controlled by consumers in community repositories.

> Note: The vision is <u>not</u> a single central repository for the nation. Rather, all of an individual's health records would be in a single account in their choice of one of multiple competing banks. Each consumer would completely control all access to their own information. Each bank would support standard withdrawal (record viewing) and deposit (adding new information) so that health care providers could use the same access protocols to work with the records in whichever bank the consumer chose.

Mission

- Promote community repositories of electronic health information under consumer control as an effective and sustainable health information infrastructure solution
- Provide assistance to communities and vendors building health record banks
- Promote necessary legislation & regulation consistent with community health record banks

Rationale

The Health Record Banking Alliance is needed to provide a feasible and effective alternative to the widely promoted concept of the "fetch and show" model for electronic records where the each person's health information is left where it is and collected and integrated each time it is needed. While this is an attractive concept in theory, it is not financially or operationally workable in practice. It fails to provide effective searching of the data for public health and medical research, and the large number of systems that would need to provide coordinated real-time response to queries around-the-clock make it expensive, unreliable, inefficient, and slow. It also cannot adequately protect health information privacy (for more details, see "Why Your Complete Lifetime Health Record Needs to be Stored in a Single Location" at http://williamyasnoff.com/?m=200605).

It is important to note that the nation's leading communities in health information infrastructure (e.g. Indianapolis, IN, South Bend, IN, Bellingham, WA, Spokane, WA, Fishkill, NY, and Cincinnati, OH) all have established central repositories. If we are going to successfully create a national health information infrastructure, we must define an approach that is feasible, understandable, and (to the greatest extent possible) is proven. Health record banking is such an approach.

Current Membership:

Private firms: Cerner, EDS, Health Data Security, NHII Advisors, Patient Command, Perot Systems, Quest Diagnostics, vIDentity Systems; *Communities:* CareEntrust (Kansas City, MO), Inland Northwest Health Services (Spokane, WA), LouHIE (Louisville, KY), State of Washington; and *Individual Members*

William A. Yasnoff, MD, PhD, FACMI, Founder & President, Health Record Banking Alliance
Dr. Yasnoff, a well-known national leader in health informatics, is Founder and Managing Partner of NHII Advisors, a consulting firm that helps communities and organizations successfully develop health information infrastructure systems and solutions. Previously, as Senior Advisor, NHII, Department of Health and Human Services, he initiated and organized the activities leading to the President's $50 million FY05 budget request and creation of the Office of the National Coordinator for Health Information Technology, establishing the NHII as a widely recognized national goal. He was elected a Fellow of the American College of Medical Informatics in 1989, and received an honorary DrPH from the University of Louisville in 2006. His MD and PhD in computer science are from Northwestern University.

For additional information about the Health Record Banking Alliance, see http://www.healthbanking.org

Health Record Banking
A Patient-Centric Solution for Electronic Health Records

Amid current concerns over health care costs and medical errors, there has been growing recognition of the need for health data to be available when and where it is needed to ensure that optimal care is delivered to patients. Health Information Technology (HIT) holds the promise of delivering significant improvements in our overall health care system by addressing this need through electronic means. However, progress toward an effective HIT solution has been slow because of problems including high costs, lack of interoperability of existing systems, and inconsistent stakeholder cooperation. In addition, concerns about patient privacy and the potential for inappropriate access to the data escalate when paper records are converted into more accessible electronic formats.

Health record banking (HRB) represents a realistic and feasible approach to created an effective HIT system. A health record bank is a trusted third party that securely collects and stores medical information on behalf of consumers, and enables each patient to fully control all access to their own data. HRBs are efficient, cost-effective, and protect individual privacy, and therefore represent a viable mechanism for delivering more complete information for each patient at any point of care. They also ensures stakeholder cooperation since the patients, rather than some new third party entity, are requesting their records from the various healthcare stakeholders.

The Problem

In today's health care environment, the complex web of interactions among providers, institutions, payers, government agencies and a myriad of ancillary services results in medical data existing in multiple forms - including a large percent in paper - and in numerous physical and electronic locations.

The exchange of data among these locations is primarily provider-oriented and driven by individual transactional needs – e.g. sending a claim to an insurer, or sending a laboratory result to a physician. The migration of these transactions from paper-based to electronic, while facilitating administrative information transmission, has not really resulted in speeding the exchange of clinically relevant information, nor has it lead to improved care delivery. It has, however, given rise to increased fear of data being accessed or used inappropriately. Well publicized breaches of consumer data have fueled these fears.

While the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule was intended to address some of these issues, it does not actually assure privacy of patient data, and offers no consumer control of or accountability for disclosures for treatment, payment, or operations (as determined solely by the holder of the data).

Complex technology systems that support multiple providers and organizations, such as Health Information Exchanges (HIEs) and Regional Health Information Organizations (RHIOs) are also driving the availability of patient information when and where needed. Unfortunately, consumers are often given little or no control over who accesses their information in such systems beyond the blunt instrument of a global opt-in or opt-out. If patients' opt out from participating in such efforts they may be denying themselves and their families the benefits such systems can offer. On the other hand, without appropriate safeguards, patients who do participate are at risk of having their data used in ways they might not have wanted and could not have anticipated.

There is considerable evidence that moving to electronic medical information promotes the use of health care data to enhance patient safety, improves the delivery of effective care, and drives down healthcare costs benefiting consumers in the long run. What is needed is a system that

can achieve these goals, while providing consumers with access and control in a way that will instill confidence while giving providers the means to deliver better healthcare.

The Solution - a Health Record Bank

A health record bank or trust is an independent organization that provides a secure, persistent, electronic repository for storing and maintaining an individual's health and medical records that assures that the individual has control over who accesses their information.

There are three critical distinguishing features of a health record bank that make it the model/framework of choice in promoting the storage and use of electronic health information:

- ***Patients control all access to the data***
  The patient controls who has access, when they have access and what they can do with it.
- ***The record is patient-centric – not provider or payer-centric.***
  The record contains data from multiple sources and providers, as opposed to only containing records for a single provider, care location or payer. Audit and tagging indicate source of the data and contribute to a "trusted source" status and promote clinical credibility by providers.
- ***The record is persistent and portable.***
  The patient's record will be persistent and will not "age off" as is typical of most clinical systems in use today. The record will persist through changes in provider or payer, and can be moved from one health record bank to another at the patient's request, without loss of data.

A health record bank can be viewed as analogous to a financial bank with information – not money – as the currency. The consumer deposits money in a financial bank for safekeeping, but the bank only retrieves, stores and disburses it as instructed by the consumer. Similarly, in the HRB the patient authorizes "deposits" of healthcare data/information and "withdrawals" from and to appropriate sources. The bank is responsible as the custodian of the information, but not the owner. The consumer owns and controls the information stored there.

In order to trust the information accessed from an HRB, providers must be assured of its reliability. Records must be tagged with the originating source, and there must be an audit trail of any changes that have occurred. Consumers may be permitted to annotate or add information, but these alterations need to be obvious to clinicians in order for them to rely on the information to help formulate clinical opinions and recommendations.

The HRB model also can offer specific features and options that might be necessary or desirable, such as supporting the concept of an agent who acts on behalf of a consumer, such as parents of minor children.

The "back-office" infrastructure of a health record bank includes secure, redundant storage, a secure network, customer contact centers and document centers. These features are already standard in other sectors of the economy and can all be built with readily available hardware, software, and systems design. It is relatively inexpensive and is already proven reliable and secure using familiar information technology methods.

The HRB approach is also compatible with current community efforts to build effective health information infrastructure, and can address some of the critical issues challenging them today.

Health record banks can achieve sustainability by providing a service that patients, as well as providers, will find valuable. Economic sustainability should be assured if patients and providers find that the service fills a need, as opposed to the economic models promoted thus far for RHIOs and other HIEs, which have not been based on a clear foundation that distributes benefits and costs appropriately. Most importantly, they address patient privacy concerns because they assure that patients have the right to control access to their data.

The health record banking model can provide the same functionality contemplated by HIEs by making more comprehensive patient data from multiple sources available to providers who need it, while truly putting the consumer's needs and rights at the forefront of the effort.

The Time is Now

The convergence of several forces – the emerging consumer empowerment movement, with its focus on the right to privacy; growing awareness of the need to battle soaring medical costs while reducing medical errors; government movement to drive the use of medical information technology combined with the dramatic improvements offered by the use of Health Information Technology - has brought us to a realization that finding a solution is both imperative and possible.

Consumer awareness of their own rights to obtain and control their health data is still an emerging phenomenon, however, the appeal of the health record banking model to consumers is intuitive as it offers them a chance to control and manage access to their information directly. As consumers become more engaged with managing their health records, if should also support them in becoming more active participants in their health care overall.

More importantly, it is highly unlikely that there will soon be a general consensus nationwide about rules to define the specific situations where access to medical information will and will not be allowed. Giving patients control over these decisions allows each person to establish their own customized privacy policy exactly suited to their needs, thereby eliminating the endless policy discussions and debates regarding uniform privacy regulations for everyone.

The needs of the health care system for appropriate access to information are critical and must be met if we are to achieve the improvements in quality and efficiency that are possible through appropriate use of Health Information Technology, but those needs must be addressed in a way that fully recognizes that the patient is at the center and their requirements for privacy deserve as much respect as their needs for care.

Health Record Banking offers a solution that supports the information needs of the health care system (providers and payers) while empowering consumers and protecting their privacy.

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March 31, 2005

<u>Biographical Sketch</u>

William A. Yasnoff, MD, PhD, FACMI

    Dr. Yasnoff is the Founder and Managing Partner of NHII Advisors, a consulting firm that helps organizations successfully develop health information infrastructure systems and solutions. Services include strategic planning and advising in areas such as generating requirements, avoiding critical mistakes, mediating internal power struggles, fundraising, solving complex governance problems among multiple stakeholders, policy development, staff recruitment, and project management. Assistance in other health informatics domains is also available, such as strategic product/service development and marketing, systems architecture, standards, messaging, and operational issues.

    Previously, Dr. Yasnoff served as Senior Advisor, National Health Information Infrastructure (NHII), U.S. Department of Health and Human Services. Beginning in late 2002, he initiated, organized, and developed the HHS activities directed at promoting and encouraging the NHII, which led to an additional $50 million in the President's FY05 budget request and the recent Presidential creation of the Office of the National Coordinator for Health Information Technology, establishing the NHII as a widely recognized goal for the nation. Dr. Yasnoff organized the NHII 2003 Conference that developed a consensus national action agenda and hosted the HHS Secretary's announcement of the historic Federal government license agreement for the comprehensive standard medical vocabulary SNOMED.

    He is an Associate Editor of the *Journal of Biomedical Informatics*, and the primary author of the chapter on public health informatics and health information infrastructure in the upcoming 3rd edition of the textbook *Biomedical Informatics: Computer Applications in Healthcare and Medicine*. Dr. Yasnoff is also Adjunct Professor of Health Sciences Informatics at Johns Hopkins, and served as a Board Member of the American Medical Informatics Association (AMIA) in 2003-4.

Before coming to the Washington, DC, area, Dr. Yasnoff was Associate Director for Science, Public Health Practice Program Office, Centers for Disease Control and Prevention (CDC), where he became well known for his work in public health informatics, including co-editing the textbook *Public Health Informatics and Information Systems*, and serving as Program Chair of the AMIA 2001 Spring meeting, "Developing a National Agenda for Public Health Informatics." He came to CDC from the Oregon Health Division, where he developed and deployed both a statewide immunization registry (still operating successfully today) and an electronic information network for public health officials.

Prior to his government service, Dr. Yasnoff spent many years in the private sector, including entrepreneurial businesses, initially as Vice President of Research for Cell Analysis Systems, Inc., where he developed the first PC-based commercial system for quantifying DNA content of cells on slides in 1986, and then as founder and ceo of his own company that developed image analysis solutions such as quantifying brain blood flow defects in SPECT scans. He later served as Medical Director of AMA/Net, the American Medical Association's first online electronic information system for physicians, developing and implementing the marketing plan that expanded the subscriber base tenfold to 40,000 in 60 days. He subsequently restarted the network as U.S. HealthLink, a public-private partnership in Oregon. He also has done consulting work for a variety of commercial, academic, and government clients, addressing a wide range of health informatics challenges, including reviewing and evaluating high-tech business plans and participating in site visits for Columbine Venture Partners.

He received both his Ph.D. in computer science (pattern recognition and image analysis) and M.D. from Northwestern University, and completed an internal medicine internship at Rush-Presbyterian St. Luke's Medical Center in 1980. Dr. Yasnoff has been a faculty member for numerous informatics courses, is the author of over 200 scientific publications and presentations, and was elected a Fellow of the American College of Medical Informatics in 1989.